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Research, Engagement, and Public Bioethics: Promoting Socially Robust Science

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Abstract

Citizens today are increasingly expected to be knowledgeable about and prepared to engage with biomedical knowledge. In this article, I wish to reframe this ‘public understanding of science’ project, and place fresh emphasis on *public understandings of research*: an engagement with the everyday laboratory practices of biomedicine and its associated ethics, rather than of specific scientific facts. This is not based on an assumption that non-scientists are ‘ignorant’ and are thus unable to ‘appropriately’ use or debate science; rather, it is underpinned by an empirically-grounded observation that some individuals may be unfamiliar with certain specificities of particular modes of research and ethical frameworks, and, as a consequence, have their autonomy compromised when invited to participate in biomedical investigations. Drawing on the perspectives of participants in my own sociological research on the social and ethical dimensions of neuroscience, I argue that public understandings of biomedical research and its ethics should be developed both at the community level and within the research moment itself, in order to enhance autonomy and promote more socially robust science. Public bioethics will have play a key role in such an endeavour, and indeed will contribute in important ways to the opening up of new spaces of symmetrical engagement between bioethicists, scientists, and wider publics – and hence to the democratisation of the bioethical enterprise.

Keywords

Neuroscience; Public Bioethics; Public Engagement; Public Understanding of Science; Research Ethics

Introduction

Today, individuals in many ‘Western’ nations, such as the UK, are increasingly expected by policymakers, health professionals and a range of other actors to be knowledgeable about and prepared to engage with biomedicine; to learn and integrate into everyday life insights from research areas as disparate as embryology, genetics, gerontology, neuroscience, and psychology. At the same time, increasing the breadth and depth of public knowledge about science has come to be understood as a valuable mechanism for ensuring public support for and trust in biomedicine (and policies that are informed by it).^{1,2} In this article, I wish to reframe this ‘public understanding of science’ project (commonly known as PUS), and argue for fresh emphasis on developing *public understandings of research*: a familiarity with the routine laboratory practices of biomedicine and its associated ethics, rather than a rote learning of specific scientific facts. In contrast to PUS advocates, I advance this paradigm not necessarily as a means of improving public trust in science and scientists, but to enhance

individual autonomy. I argue that in order to ensure a socially robust biomedical enterprise, the public understanding of research and its ethics should be ensured both at the community level and within the research moment itself.

The example of autonomy and the practices of informed consent constitute a useful lens through which to view the warrant for such a paradigm. Whilst I do not claim that the promotion of autonomy is necessarily always the most important value underpinning ethical frameworks in the biosciences, it is unquestionably one which has attracted the attention of many scholars and commentators and is enshrined within much ethics governance. The concept of autonomy, as promoted through informed consent practices, gains a salience through this bioethical traction that makes it a useful focus around which to form the analysis presented herein.

To further illustrate these points, I draw on the perspectives of participants in my own empirical sociological research on the social and ethical dimensions of neuroscience. The individuals cited here belong to diverse biosocial groups (e.g. individuals living with dementia and epilepsy, and recovering from head injury), and the talk elicited was obtained from 16 small focus groups (3-5 participants) within which the topic of the place, role and impact of brain research on society provided momentum for discussions which often went far beyond these themes to include the rights of research participants, the politics of science, and the relationships between doctors, patients and scientists.

Contextualising Knowledge

I really don't know much about neuroscience. (Mabel, head injury patient)

As noted above, the furthering of the 'public understanding of science' has been an animating concept within much recent science policy and practice. Recently, this agenda has shifted somewhat, focusing more on public engagement *with* science. Whilst recognising the importance of an appreciation of scientific knowledge, models of engagement are commonly committed to ensuring dialogue between scientists and wider publics – potentially contributing to more socially-robust science.³

In spite of this new initiative to educate and engage non-scientists, within the focus groups I convened statements such as "I really don't know much" about science were commonly advanced. However, the same individuals who might profess ignorance about science may yet demonstrate knowledge about its institutional structures, and researchers' motivations for their work.⁴ Nevertheless, understandings of the complexities of contemporary biomedical investigations cannot be assumed; the realities of scientific research may be very different to people's expectations, and participants may be unclear regarding the scope and nature of the studies in which they are participating.^{5,6}

This is an issue that is well-known to those who work at the 'coal face' of science, and has significant implications for the ethical conduct of research. Perhaps the most obvious example is the case of informed consent, where an understanding of the research process and its ethical foundations is vital to ensure participant autonomy.⁷ If research participants do not understand the research trajectory, the mechanisms by which it will be undertaken, the kinds of ethical regulations governing it, and its likely impact within the field and in society, fully informed consent cannot be obtained; autonomy is compromised through incomplete or inaccurate knowledge. Where scientists are aware of this, allowing continued participation is ethically questionable. In particular, there are serious issues revolving around unrealistic expectations of research, and uncertainties regarding proper ethical conduct.

Managing Expectations

I don't see the point in having science for science's sake. (Joan, head injury patient)

An important aspect of the public understanding of research involves managing expectations. Again, this is an issue that is faced by investigators across the professional life-course, and requires significant work. Often, there is a necessity to promote 'basic' science and to articulate its utility both to the clinic and to biomedicine more broadly (in order to garner funding, recruit participants, and impact upon policy and clinical practice). As Joan's comments above suggest, some people are disinclined to support such studies, and thus their participation in research is less likely. However, if an individual openly expressing beliefs like Joan's does agree to take part in research, it is the investigator's duty to discuss the realistic limits – as well as the implicit import - of their work (especially in cases where participation comes at some kind of cost).

On the other hand, (potential) research participants can have unrealistic understandings of the speed with which developing therapies may move from the bench to the bedside.⁸ Consequently, individuals may volunteer to participate in studies because they believe it will lead directly to a therapeutic intervention, and because they regard their contribution as singularly important - and even potentially beneficial to their own health. In some cases these beliefs may be fully justified. Yet, more often, many years might pass before effective therapies are realised (if indeed they are at all). Whilst an altruistic imperative on behalf of research participants must not be discouraged, it should always be carefully handled - not solely within the research moment, but also within the kinds of interactions (e.g. public engagement) that serve to pre-define this. At the same time, however, it remains important to refrain from assuming that all research participants are necessarily under the 'therapeutic misconception', since some individuals may be well aware of the 'research-only' nature of the biomedical investigation in which they are taking part.⁹

Clarifying Uncertainties

I always worry if they find out if I've maybe got Parkinson's would they tell me?
Or would they pass it on to my doctor or just all hush, hush, 'discovered this but we're not telling you', you're in the dark. (Greg, dementia patient)

The individuals who participated in my research - including those who had participated in neuroscientific studies, those who would consider it, and those who could not imagine doing so - valued openness and honesty on the part of biomedical investigators. This was especially evident in discussions of confidentiality. However, some recognised that there are limits to disclosure, leading to uncertainties regarding what scientists might do with clinically-significant data (as illustrated above). Indeed, these concerns can be seen to be expressed in the scientific community itself, as scientists may sometimes be uncertain regarding what, precisely, they should do if, for instance, they generate clinically-significant incidental findings during the course routine research.^{10,11} The concerns of Greg and many other members of the 'lay' public might (and sometimes likely do) translate into a disinclination to take part in research at all. To an extent, apprehensions like Greg's can be put to rest as part of existing consent practices. Yet, this relies on individuals considering participation in the first place.

Assuming participation is at least being contemplated, highlighting and perhaps clarifying ethical uncertainties enhances the autonomy of participants and wider publics through empowering them to enter into discussions with scientists about their work. This has various implications. Most obviously, dialogue assists participants in identifying whether they are being treated ethically by the standards of most biomedical institutions and practitioners

(though of course the responsibility for appraising the ethical robustness of studies should not be *transferred* to participants). This is perhaps especially important for so-called 'professional guinea-pigs', who are engaging in biomedical research for explicitly financial reasons.^{12,13} More profoundly, as we will see, it contributes to a new kind of ethical agenda-setting.

Thinking through Engagement

How might we contribute to enhancing public understanding of research and its ethics? This is no single or simple answer to this. One of several solutions might be to further knowledge within the research encounter itself. However, this cannot be restricted to the consent form. More useful might be an impartial third party to discuss issues around research and ethics prior to consent.⁷ Yet, the question remains: how can a member of a scientific team truly be impartial? Furthermore, there is something to be said about the overburdening of participants with information being *contrary* to autonomy. Last, beliefs about science, developed over the life-course, may be resistant to recalibration through a single event.

Thus, we might look first towards our educators to embed understandings of research and its ethics within pedagogy concerning science. Whilst this may be within the classroom, it also behoves biomedical investigators to incorporate discussion of the everyday work and ethical dilemmas of science into presentations, lectures and other forms of dissemination that aim to promote public scientific literacy. Such engagement could well include dialogue and debate about translational science, highlighting the need for individuals to take part in basic research, whilst also acting to enhance the autonomy of those potential participants by informing them of the realities (including scope and limits) of scientific practice. Discussions of ethics will help to ensure that uncertainties about research practices (e.g. what scientists are likely to do with incidental findings) are reduced (with the potential side-effect that some 'barriers' to participating in research are dismantled).

We can, therefore, see that a commitment to a public understanding of research agenda also increases the need for and role of bioethicists and other analysts of the ethical dimensions of science within civil society. Experts in biomedical ethics will necessarily work closely with science educators in order to enhance public debate and education.¹⁴ In so doing, the scope of 'public bioethics' will extend beyond the confines of institutionalised spaces of carefully proscribed, instrumental and narrowly defined deliberation, and extend far further than the occasional media interview or newspaper contribution. This is not, of course, to advocate for some kind of colonial expansion of bioethics. Rather, it is an acknowledgement of the liminality of bioethicists - that their 'proper' place is neither completely within or outwith biomedicine - and the recognition that as such these disciplinary experts are ideally positioned to engage different social worlds with one another. Arguably, there is, perhaps, even a moral duty to do so, if the development of public understandings of research and its ethics is indeed accepted as having potential to enhance (for instance) participant autonomy.

None of the above, though, should be read as an assertion that 'the public' itself has any kind of obligation to become 'educated' in the art of scientific research. This would be a resurrection of the 'deficit model' of the public understanding of science which social scientists and others have fought hard to reconstruct within policy and the academy. It is not the case that publics are ignorant in some global sense and are thus unable to appropriately engage with science; rather, particular individuals and social groups may be unfamiliar with some of the specifics of certain modes of research and ethical frameworks, and, as a consequence, have their autonomy compromised when they come to participate in studies. If blame for this lack of public familiarity with the processes of research were to be apportioned anywhere - and I am not convinced that this would be a particularly fruitful

venture - then it might perhaps be placed on biomedical institutions themselves for emphasising the necessity of the public consumption of scientific facts rather than the mechanisms and means by which these generated; to find fault with the 'ignorance' of those non-expert publics whose research participation is essential to the constitution of such knowledge seems somewhat unfair. .

We should also remember that the nuances of publics' knowledge can only be fully appreciated if we listen to what they themselves have to say about the meanings of research and its ethics, and to carefully regard their related concerns. Such dialogue could be developed through a range of initiatives, including deliberative events, science communication blogs, and other internet-based social media.¹⁵ The research tools of the social sciences (participant observation, interviews, focus groups and so on) would also play an important role (though in the process scholars in these traditions must necessarily also commit themselves to promoting wider public understandings and engagement with social science research and ethics).

Broad public dialogue and debate, and empirical social research into this, would serve several inter-related functions. Clearly, and most practically, it would locate any common uncertainties individuals and groups may have regarding particular types of biomedical research. These could then be addressed through wider education and engagement. However, listening and responding to public accounts of research and its ethics could also challenge prevailing notions over what counts as 'ethical', and who gets to adjudicate this. Arguably, it is paternalistic to assume a particular practice (e.g., failure to directly notify an individual of clinically-relevant incidental findings after taking part in research) is unethical if participants themselves consider, on reflection, it to be acceptable. After all, as sociologists have shown, a variety of individuals can enjoy carefully reasoned, informed debate about bioethics.^{1,2,4,16} Where ambivalence is evident, we might best regard this not as a 'failure' to formulate a normative agenda, but instead as evidence that the issue in question is more complex than we, as active researchers, have perhaps supposed.³ In sum, new forms of dialogue around research and its ethics will open up new spaces for symmetrical engagement between bioethicists, scientists and wider publics, contributing to the broader democratisation of the bioethical enterprise.

Conclusion

Using the example of informed consent, I have argued that the public understanding of biomedical research and its ethics should be a key focus of those concerned with the ethical dimensions of biomedicine. Differing perspectives between participants and researchers decreases the capacity of the former to consent to the investigations of the latter in meaningful ways, compromising autonomy. Equally, particular assumptions made about the research process may result in potential participants never choosing to involve themselves in studies to begin with. To address these issues, the onus is on bioethicists, scientists and their respective institutions to engage more willingly and coherently with publics concerning the everyday ethics and practices of research, as well as on science educators to ensure that the messy realities of scientific life are embedded within communication of biomedical knowledge. More radically, a public bioethics should also consider how those working within biomedicine can be more responsive to the ethical sensibilities of non-specialists. For formal bioethics to fail to account for publics' own perspectives on the research that they may be invited to participate in is, ultimately, untenable. The approaches of sociologists committed to critical PUS research represents one of several useful departure points for this work. Such a move presents us with a valuable opportunity to further develop participatory moves in public bioethics, extend the democratisation of science, and produce a more socially-robust biomedical enterprise. At the same time, however, we must be cautious about

generating novel forms of expertise through the activities of public bioethics, and, hence, the potential for new ways of figuring publics as ‘ignorant’.¹⁷

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